# **Unmet Need**

Regular medical care and treatment adherence are key to successfully managing HIV disease (see section, "HIV Care Continuum"). Monitoring of HIV viral load (VL) and CD4 cell counts are part of routine medical care for persons living with HIV disease (PLWHA). VL should be measured at least every three to four months. For patients whose VL has been suppressed for >2–3 years and whose clinical and immunologic status is stable, this can be reduced to every six months (Aberg et al., 2013). CD4 cell counts should also be monitored every three to four months. For patients on antiretroviral treatment (ART) whose CD4 counts have increased above the threshold for opportunistic infection risk, the counts can be monitored every 6–12 months (Aberg et al., 2013).

PLWHA are considered to have an unmet need for HIV-related care (or, to be out of care) when there is no evidence of receiving regular HIV primary health care (Kahn, Janney, and Franks, 2003). To estimate receipt of primary health care, data indicating provision of any of the following three components of HIV primary care during a defined 12-month period are used: VL testing, a CD4 cell count, or ART prescription.

Illinois requires reporting of all VLs – both detectable and undetectable, all CD4 test results, and all subtype and sequence data from antiviral drug resistance testing. These data are reported to IDPH and maintained in eHARS (see section, "Data Sources"). Because a significant proportion of PLWHA receive antiretroviral medications through the state's AIDS Drug Assistance Program (ADAP), the ADAP database is used to provide data on persons receiving ART, as well as information on VLs and CD4 counts (see section, "AIDS Drug Assistance Program"). The Illinois Medicaid program served more than 15,200 PLWHA in 2013 and is an additional source of data to estimate the number of persons in care.

To estimate unmet need in Illinois in 2013, eHARS data for individuals who were diagnosed with HIV disease through December 31, 2012 and alive as of December 31, 2013 were utilized. Persons diagnosed in 2013 were excluded from this analysis because there are a significant number of newly diagnosed cases for which the defined 12-month period to obtain HIV primary medical care had not lapsed. As of Dec 31, 2013, there

were 34,250 persons diagnosed with HIV/AIDS in Illinois through December 31, 2012 and living as of December 31, 2013 (18,742 people living with AIDS (PLWA) and 15,508 people living with HIV (PLWH)). Calculations for estimates of unmet need are described in Table 1.

### **Unmet Need Estimation**

In 2013, approximately 13,708 of 34,250 PLWHA in Illinois or 40.0% had unmet need for care and treatment. Unmet need differs by disease status because care patterns vary based on illness severity (Kahn et al., 2003). Among persons living with HIV who had not progressed to AIDS (PLWH), this percentage was 44.4% while among PLWA it was 36.4%.

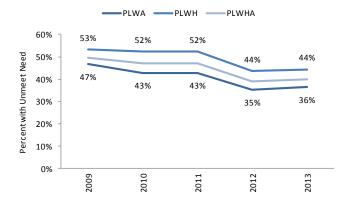
Table 1. Unmet Need Estimate Analysis, Illinois, 2013

Table 1. Unmet Need Estimate Analysis, Illinois, 2013								
	Number/							
	Percent	Data Source						
Population Sizes								
A. Number of persons living								
with AIDS (PLWA), 2013	18,742	2013 eHARS						
B. Number of persons living								
with HIV (PLWH non-								
AIDS/diagnosed), 2013	15,508	2013 eHARS						
Care Patterns	Care Patterns							
C. Number/percent of PLWA		2013 VL or CD4						
received specified primary		Lab Reports or						
medical care services in 12-		Linked Service						
month period	11,915/63.6%	Providers						
D. Number/percent of								
PLWH diagnosed, non-AIDS)		2013 VL or CD4						
received specified primary		Lab Reports or						
medical care services in 12-		Linked Service						
month period	8,627/55.6%	Providers						
Calculated Results								
E. Number of PLWA did not								
receive primary medical								
services	6,827							
F. Number of PLWH								
(diagnosed, non-AIDS,) did								
not receive primary medical								
services.	6,881							
G. Total HIV+/diagnosed not								
receiving specified primary								
medical care services								
(estimate of unmet need)	13,708							

Source: Illinois Department of Public Health, 2014

Rates of unmet need in Illinois declined among both PLWA and PLWH from 2009–2013, even as the statewide total of PLWHA increased (see section, "Overview of HIV Disease in Illinois").

Figure 1. Estimated Unmet Need among Persons
Living with HIV Disease by Disease
Progression and Year, Illinois, 2009–2013\*



<sup>\*</sup>Reporting sources varied over time, which may affect comparability of estimates across years

Source: Illinois Department of Public Health, 2014

#### Sex

Among PLWHA, unmet need was slightly higher among males (41%) compared to females (38%). Among PLWH, unmet need was similar among men and women. However, among PLWA, men were more likely than women to have unmet need.

Figure 2. Estimated Unmet Need among Persons
Living with HIV Disease by Disease
Progression and Sex, Illinois, 2013



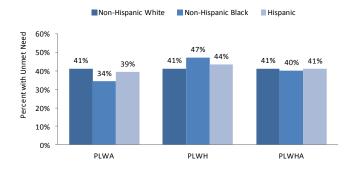
Source: Illinois Department of Public Health, 2014

### Race/Ethnicity

Overall rates of unmet need for PLWHA were similar among non-Hispanic (NH) whites, NH blacks, and

Hispanic individuals. Among PLWA, NH blacks had lower rates of estimated unmet need compared to NH whites and Hispanics. However, among PLWH, NH blacks had higher estimated unmet need.

Figure 3. Estimated Unmet Need among Persons
Living with HIV Disease by Disease
Progression and Race/Ethnicity, Illinois, 2013

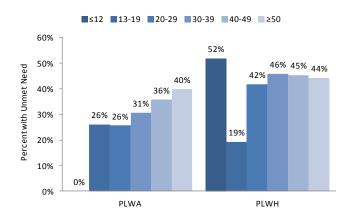


Source: Illinois Department of Public Health, 2014

#### Age

Among PLHA, unmet need increased with increasing age with adults ≥50 years having the highest rates. Among PLWH, children ≤12 years had the highest rates of unmet need. Among PLWH aged ≥30 years, unmet need rates were similar at around 45%.

Figure 4. Estimated Unmet Need among Persons Living with HIV Disease by Disease Progression and Age, Illinois, 2013



Source: Illinois Department of Public Health, 2014

#### Transmission Risk Category

The largest number of persons living with HIV disease in Illinois are MSM and this risk group makes up the largest number of persons with unmet need among both PLWA and PLWH. In 2013, there were 6,499 MSM with unmet need in Illinois. The risk group with the

highest proportion of unmet need in 2013 were individuals whose risk factor for HIV infection was not reported or unknown. Among PLWHA in this transmission risk category, almost 80% had unmet

need. The reasons for this higher level of unmet need are not clearly understood. PLWHA who were IDUs had the second highest rate of unmet need (46.4%).

Table 2. Estimated Unmet Need among Persons Living with HIV Disease by Disease Progression and Transmission Risk Category, Illinois, 2013

	Risk	Unmet Need	Met Need	Total	Percent Unmet Need
PLWA	MSM	3,380	5,874	9,254	36.5%
	Injection Drug Use (IDU)	1,130	1,569	2,699	41.9%
	MSM+IDU	416	764	1,180	35.3%
	Heterosexual	978	2,026	3,004	32.6%
	Transfusion/Hemophilia	30	70	100	30.0%
	Mother with, or at risk for HIV infection	46	97	143	32.2%
	Other	527	1,379	1,906	27.6%
	Risk not reported/Unknown	320	136	456	70.2%
	Total	6,827	11,915	18,742	36.4%
PLWH	MSM	3,119	5,043	8,162	38.2%
	Injection Drug Use	751	602	1,353	55.5%
	MSM+IDU	204	281	485	42.1%
	Heterosexual	914	1,276	2,190	41.7%
	Transfusion/Hemophilia	12	14	26	46.2%
	Mother with, or at risk for HIV infection	77	131	208	37.0%
	Other	1,118	1,129	2,247	49.8%
	Risk not reported/Unknown	686	151	837	82.0%
	Total	6,881	8,627	15,508	44.4%
PLWHA	MSM	6,499	10,917	17,416	37.3%
	Injection Drug Use	1,881	2,171	4,052	46.4%
	MSM+IDU	620	1,045	1,665	37.2%
	Heterosexual	1,892	3,302	5,194	36.4%
	Transfusion/Hemophilia	42	84	126	33.3%
	Mother with, or at risk for HIV infection	123	228	351	35.0%
	Other	1,645	2,508	4,153	39.6%
	Risk not reported/Unknown	1,006	287	1,293	77.8%
	Total	13,708	20,542	34,250	40.0%

Source: Illinois Department of Public Health, 2014

# Geography

The Chicago Region has the highest number of PLWHA though, the proportion with unmet need was slightly lower than the overall state average (39% vs. 40%).

The Peoria Region had the highest proportion of PLWHA with unmet need (57.2%).

Table 3. Estimated Unmet Need among Persons Living with HIV Disease by Disease Progression and Region, Illinois, 2013

	Region	Unmet Need	Met Need	Total	Percent Unmet Need
PLWA	Winnebago Region	527	442	969	54.4%
	Peoria Region	213	180	393	54.2%
	Sangamon Region	165	265	430	38.4%
	St. Clair Region	217	408	625	34.7%
	Jackson Region	87	119	206	42.2%
	Champaign Region	212	312	524	40.5%
	Collar Region	577	1,036	1,613	35.8%
	Suburban Cook Region	819	1,810	2,629	31.2%
	Chicago Region	4,010	7,343	11,353	35.3%
	Total	6,827	11,915	18,742	36.4%
PLWH	Winnebago Region	159	236	395	40.3%
	Peoria Region	218	142	360	60.6%
	Sangamon Region	189	193	382	49.5%
	St. Clair Region	302	323	625	48.3%
	Jackson Region	121	94	215	56.3%
	Champaign Region	211	209	420	50.2%
	Collar Region	550	698	1,248	44.1%
	Suburban Cook Region	757	976	1,733	43.7%
	Chicago Region	4,374	5,756	10,130	43.2%
	Total	6,881	8,627	15,508	44.4%
PLWHA	Winnebago Region	686	678	1,364	50.3%
	Peoria Region	431	322	753	57.2%
	Sangamon Region	354	458	812	43.6%
	St. Clair Region	519	731	1,250	41.5%
	Jackson Region	208	213	421	49.4%
	Champaign Region	423	521	944	44.8%
	Collar Region	1,127	1,734	2,861	39.4%
	Suburban Cook Region	1,576	2,786	4,362	36.1%
	Chicago Region	8,384	13,099	21,483	39.0%
	Total	13,708	20,542	34,250	40.0%

Source: Illinois Department of Public Health, 2014

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